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A SPECIAL DIABETES SURVEILLANCE EVALUATIVE STUDY: THE NORTH CAROLINA REGISTER OF THE BLIND AND VISUALLY IMPAIRED

by

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ABSTRACT

North Carolina's State Center for Health and Environmental Statistics was awarded a three-year cooperative grant from the Centers for Disease Control to develop a surveillance system for diabetes-related mortality and morbidity. Statewide data sets were evaluated for their ability to monitor North Carolina's diabetic population with respect to their medical care and treatment, complications, and mortality, as well as to determine diabetes prevalence rates.

Persons with diabetes are at risk for developing circulatory, neurological, and renal system disorders. In their most debilitating forms, many of these disorders can be tracked using hospital discharge data. However, it is unlikely that the severe visual impairment or blindness that is many times associated with diabetes will ever result in a hospital stay, and therefore cannot be adequately monitored with hospital discharge data.

One of the only population-based registries of the blind and visually impaired in the United States is maintained by North Carolina's Division of Blind Services. This registry includes information regarding the cause of visual impairment or blindness, and therefore its usefulness in tracking cases caused by diabetes was assessed.

An evaluation of the North Carolina Register for the Blind and Visually Impaired reveals that while the data set has enormous possibilities for statewide surveillance of diabetes-related visual disability, it is fraught with many difficulties. Due to its primary evolution as a tool for service delivery, much of the information of foremost interest for monitoring purposes is missing or unknown. For all practical purposes, there is no quality control with respect to etiology or demographic data, and the overall level of compliance is unknown.

However, with improvements in quality control and more vigorous enforcement of the reporting mandate, the Register could be an effective monitoring tool for diabetes-related blindness. With these improvements, its value could go far beyond its utility for statewide planning. The North Carolina Register for the Blind and Visually Impaired has the potential to make a real contribution nationally; it could become virtually the only system in the country with reliable statewide information on diabetes-related blindness and visual impairment.

INTRODUCTION

The State Center for Health and Environmental Statistics (SCHES) instituted a statewide surveillance system for diabetes-related mortality and morbidity with funding from the Centers for Disease Control. A study of the number of diabetes-related deaths and crude and age-adjusted mortality rates in North Carolina revealed significant increases from 1980 through 1989.[1] Persons with diabetes also suffer disproportionately from a variety of medical complications, particularly those affecting the circulatory, neurological, and renal systems.[2] Hospitalization data were used to better describe diabetes-related complications in North Carolina by age, sex, and county.[3] However, one of the most serious complications of diabetes — that of visual impairment or blindness — would be unlikely to cause hospitalization, and would therefore be inadequately monitored using a data set of hospital discharges.

The Department of Human Resources' Division of Blind Services maintains a Register of the Blind and Visually Impaired which is better suited to analyze and track cases of blindness caused by diabetes than are hospital discharge data files. Mandated in 1935, the Register began to collect diagnosis, etiology, and demographic information on all legally blind individuals in the state. Some doctors also choose to report instances of severe visual impairment. Currently about 28 percent of the Register's 33,905 records are individuals with significant impairment; the remainder are legally blind. Using data elements from the Register, this study will describe those whose blindness or visual impairment was caused by diabetes.

Deterioration of the retinal microvascular vessels is almost an inevitable consequence of long-standing diabetes.[4] One large epidemiologic study found that 97 percent of patients with insulin-dependent diabetes mellitus (IDDM) of 15 years duration exhibited some degree of retinopathy, as did about 60 percent of older-onset, noninsulin-dependent patients (NIDDM).[5] While diabetic retinopathy does not lead inevitably to blindness, it is the leading cause of new cases of blindness among people from age 20 through 44.[6] Among those aged 45 through 74, retinopathy is the second leading cause. Diabetes is also a risk factor for glaucoma, another leading cause of blindness.

Early detection and laser photocoagulation treatment of diabetic retinopathy can prevent up to 60 percent of diabetes-related blindness or severe vision loss.[4] Such treatment is widely available but greatly underutilized. It is estimated that a 45 percent reduction in the incidence of diabetes-related blindness could be achieved by the year 2000 if the public and professionals were better educated regarding the importance of early detection and surgical interventions.[6]

DATA

As mandated since 1935, physicians have been sending eye reports of the legally blind to the Division of Blind Services' Register of the Blind and Visually Impaired. These reports classify the causes of severe visual impairment and blindness by the site and type of affection (e.g. retina/retinopathy, retina/macular degeneration) using guidelines established by the National Society for the Prevention of Blindness. Each case is further classified by etiology (e.g. infectious and other disease, injuries, poisonings). Table 1 enumerates the data items currently captured by the Register.

While etiology codes were always among the required information on the physician eye reports, the Register ceased to key them into their computerized database in 1989. The Register has primarily been maintained as a tool for service delivery rather than for statistical purposes, and consequently there was little interest in the etiology field. However, as etiology codes are the only means of attaching a specific cause (such as diabetes) to a site and type diagnosis, the State Center pursued the development of a Memorandum of Agreement with the Division of Blind Services to allow the abstraction of missing etiology codes from hard-copy records and the merging of those codes into the database.

TABLE 1
NC BLIND REGISTER DATA ITEMS

1. County of residence
2. Last name
3. First name
4. Middle initial
5. Birth date
6. Sex
7. Race
8. Vision group
   (degree of blindness or visual impairment)
9. Hearing impaired
10. Date diagnosed
11. Diagnosis
    (classification by site and type of affection)
12. Etiology
13. Institutionalized

The resulting complete data file was tabulated in February 1992. It is a "point-in-time" file rather than a file of new cases added during a specific time period. It includes anyone in the state who has ever been reported as legally blind or visually impaired minus those who are known to have died.

While physicians are required by law to submit eye reports for those who are legally blind, compliance with the mandate has never been determined. Nor is there validation of the data submitted on the reports; much of the information is left blank or may be inaccurate (particularly diagnosis and etiology fields). So, while there is far more information regarding diabetes and blindness or visual impairment in the Register than would be available using any other source with statewide coverage, the data are by no means complete, and the level of accuracy with respect to diagnoses and etiologies is suspect.

RESULTS

Of 33,905 records, 3,243 listed diabetes as the primary cause of blindness or visual impairment. Seventy percent (2,256) of these individuals were legally blind, while 30 percent (987) had a significant degree of visual impairment due to diabetes (Table 2).

The National Society for the Prevention of Blindness guidelines also classify multiple causes of blindness: etiology code 9501 specifies senile degeneration and diabetes mellitus, with or without other etiology, and code 9503 is the classification for diabetes mellitus and other etiology except senile degeneration. Using these codes, an additional 209 cases of blindness or visual impairment could be attributed *in part* to diabetes.

Diabetes is the fourth most common etiology in the Blind Register data file (Table 3). Most frequently encountered, however, is classification 9900, "etiology not established on examination or not reported" with 8,423 records. "Unknown to science" (9100) is third with 3,887 cases. The percent of unknown and missing etiologies has increased since the period 1979-1987. The percent unknown and missing during that period varied between 27 and 40. Since 1988,

TABLE 2
NUMBER OF RECORDS BY ETIOLOGY AND SEVERITY OF VISUAL IMPAIRMENT
NORTH CAROLINA, FEBRUARY 1992

	All records	Diabetes	No diabetes
Total number of records	33,905	3,243	30,662
Legally blind	24,371 (72%)	2,256 (70%)	22,115 (72%)
Visually impaired	9,534 (28%)	987 (30%)	8,547 (28%)

however, the percent has been close to 50 percent. "Senile degeneration indicated" (6221) and "senile degeneration assumed" (6222) combined is the leading *known* cause of blindness or visual impairment, with diabetes being the second leading known cause.

TABLE 3
LEADING CAUSES OF BLINDNESS AND SEVERE VISUAL IMPAIRMENT
NORTH CAROLINA, FEBRUARY 1992

Etiology	All records
1. Unestablished or missing	8,423
2. Senile degeneration	7,394
3. Unknown to science	3,887
4. Diabetes	3,243
5. Hereditary origin	3,113

There were more females (59 percent) than males (41 percent) in this data set (Table 4). Of those records with a diabetes etiology, 67 percent were female. At least a partial explanation of the difference by gender may be that the highest prevalence rate of diabetes itself is in black females.[7] Some of the literature also suggests that proliferative retinopathy (the most severe form) is more common in females than in males[8] and that it may be associated with the stage of sexual development, as reflected by menarchal status.[9] Pregnancy is also thought to have a deleterious effect on retinopathy.[4]

In general, diabetes is far more prevalent in blacks than whites.[7] During the period 1980-87, the national diabetes prevalence rate for black males was 1.4 times that for white males, and black females had a rate approximately two times that for white females. As one might expect, then, there was a higher percent of blacks represented in the records with an etiology of diabetes (40 percent) compared with records with no mention of diabetes (34 percent).

The average age at which an individual is reported to the Register does not appear to vary significantly with the diagnosis of diabetes. The mean age of those whose impairment was caused by diabetes was 53, while the mean age of those with another or unknown cause was 56. Some studies indicate that the earlier a patient is diagnosed with diabetes, the more likely they are to develop retinopathy, and the more likely that the damage will progress to its most severe form.[9,10] However, others have indicated that it is not the age at onset that is important in the development of sight-damaging retinal lesions, but only the duration of the diabetes.[8]

TABLE 4
DEMOGRAPHICS IN THE BLIND AND VISUALLY IMPAIRED POPULATION
NORTH CAROLINA, FEBRUARY 1992

Gender	All records	Diabetes	No diabetes
Male	13,902 (41%)	1,072 (33%)	12,830 (42%)
Female	19,878 (59%)	2,170 (67%)	17,708 (58%)
Missing	125 (0%)	1 (0%)	124 (0%)
Race			
White	19,101 (57%)	1,441 (45%)	17,660 (58%)
Black	11,722 (35%)	1,288 (40%)	10,434 (34%)
Missing or other	3,082 (9%)	514 (15%)	2,568 (8%)
Age			
Mean age when add to Registry	53	56	53

Mean age by race/sex-group differed significantly for those whose blindness or visual impairment was due to diabetes (Table 5). At an average age of 49, white males were the youngest at the time of diagnosis, with black males diagnosed as legally blind on average at age 54. Females tended to be diagnosed later — white females at 58, and black females at 60.

Nearly two-thirds of the records indicate the degree—if any—of hearing impairment (the remainder of the records have missing data). Only one percent of those who have lost or impaired sight due to diabetes are also hearing impaired; three percent of non-diabetics have difficulty hearing (Table 6).

About five percent of diabetic individuals were found to be institutionalized, compared with 13 percent of those without diabetes (Table 7).

A list of leading diagnoses by site and type looks very different depending on whether an individual had an etiology of diabetes or not. The most frequently coded diagnoses for those without diabetes were (in order from more to less frequent): 1) cataracts, 2) macular degeneration, 3) unestablished or missing, 4) glaucoma, and 5) optic nerve atrophy (see Table 8). Nearly 87 percent of individuals with diabetes, however, had a diagnosis of retinopathy. Cataracts, unestablished causes, and macular degeneration are relatively rare diagnoses for the visually impaired diabetic.

TABLE 5
MEAN AGE BY RACE/SEX GROUP FOR THOSE WHOSE BLINDNESS OR VISUAL IMPAIRMENT IS DUE TO DIABETES
NORTH CAROLINA, FEBRUARY 1992

Race/Sex	Number	Age
White Males	571	49
White Females	867	58
Black Males	303	54
Black Females	982	60
Unknown sex or race	513	54

DISCUSSION

Visual impairment or blindness are serious complications associated with the chronic disease of diabetes. While eye diseases are not fatal, they have caused suffering, disability, and loss of productivity for thousands of people in North Carolina. Nationally, diabetes is the leading cause of blindness among people aged 20 through 44, and the second leading cause from ages 45 through 74. Diabetic retinopathy is the most common diagnosis attached to these cases, although diabetes is also a risk factor for glaucoma.

TABLE 6
HEARING IMPAIRMENT IN THE BLIND AND VISUALLY IMPAIRED POPULATION
NORTH CAROLINA, FEBRUARY 1992

Hearing status	All records	Diabetes	No diabetes
No hearing loss	20,528 (61%)	2,094 (65%)	18,434 (60%)
Hearing impaired	945 (3%)	42 (1%)	903 (3%)
Missing	12,432 (37%)	1,107 (34%)	11,325 (37%)

TABLE 7
INSTITUTIONALIZATION IN THE BLIND AND VISUALLY IMPAIRED POPULATION NORTH CAROLINA, FEBRUARY 1992

Institutional status	All records	Diabetes	No diabetes
Not in institution	26,176 (77%)	2,556 (78%)	23,620 (77%)
Institutionalized	4,000 (12%)	152 (5%)	3,848 (13%)
Missing	3,729 (11%)	535 (16%)	3,194 (10%)

TABLE 8
LEADING DIAGNOSES BY ETIOLOGY NORTH CAROLINA, FEBRUARY 1992

Leading diagnoses:	No diabetes	Leading diagnoses:	Diabetes
1. Cataracts	6,161	1. Retinopathy	2,963
2. Macular degeneration	4,209	2. Cataracts	67
3. Unestablished or missing	3,997	3. Cataract & retinal affection	60
4. Glaucoma	3,608	4. Not established or unknown	24
5. Optic nerve atrophy	1,609	5. Macular degeneration	16

As part of its CDC grant-funded diabetes surveillance activities, the State Center obtained a copy of the North Carolina Division of Blind Services' Register of the Blind and Visually Impaired data file. These data created a baseline for the establishment of a surveillance system for diabetes-related blindness and visual impairment. This study describes diagnoses and demographics of the population whose visual disabilities were primarily caused by diabetes, and contrasts them with those whose disabilities were not reported as related to diabetes.

Diabetes was found to be the fourth most common etiology in the Blind Register data file. As two higher ranking causes were "unknown to science" and "etiology not established or missing," diabetes was actually the second leading *known* cause of blindness or visual impairment behind "senile degeneration."

Nearly two-thirds of individuals whose impairment was due to diabetes were female, compared with 58 percent of those whose impairment was not diabetes-related. Blacks were also disproportionately represented among those diagnosed with diabetes.

Mean age at diagnosis of blindness or visual impairment between the two populations was similar —56 for those with diabetes, and 53 for those who were not so diagnosed. Mean age by race/sex-group differed significantly for those whose condition was due to diabetes. At age 49, white males were the youngest at the time of diagnosis, with black males diagnosed legally blind on average around age 54. Females tended to be diagnosed later—white females at 58, and black females at 60.

Those whose visual impairment or loss was due to diabetes were less frequently hearing impaired and less likely to have been institutionalized than those with no etiology of diabetes reported.

While the Register for the Blind and Visually Impaired has great potential for statewide surveillance of diabetes-related visual disability, it is a data set fraught with many problems. Due to its primary evolution as a tool for service delivery, much of the information of foremost interest for monitoring purposes are missing or unknown. For all practical purposes there is virtually no quality control with respect to etiology or demographic data, and the overall level of compliance is unknown. However, with improvements in quality control and more vigorous enforcement of the reporting mandate, the system could be an effective monitoring tool for diabetes-related blindness. Its value could go far beyond its utility for statewide planning. North Carolina's Register could become virtually the only system in the country with reliable statewide information on diabetes-related blindness and visual impairment.

REFERENCES

1. Sullivan LA. North Carolina State Center for Health and Environmental Statistics. Diabetes Surveillance: Diabetes Mortality in North Carolina from 1980 through 1989. *CHES Studies.* No. 51 (December 1991).

2. Santiago JV. Overview of the Complications of Diabetes. *Clinical Chemistry* (1986). Vol. 32, No. 10(B): B48-B60.

3. Sullivan LA. North Carolina State Center for Health and Environmental Statistics. Diabetes Surveillance: Diabetes Hospitalizations in North Carolina. *SCHES Studies.* No. 69 (July 1992).

4. Kohner EM. Diabetic Retinopathy. *British Medical Bulletin* (1989). Vol. 45, Vol.1: 148-173.

5. Klein R, Klein BEK, Moss SE, Davies MD, DeMets DL. The Wisconsin Epidemiologic Study of Diabetic Retinopathy. II Prevalence and Risk of Diabetic Retinopathy when Age at Diagnosis is Less than 30 Years. *Arch. Ophthalmology* 1984. No. 102: 520-526.

6. Public Health Service. *Healthy People 2000: National Health Promotion and Disease Prevention Objectives.* US Department of Health and Human Services, September 1990: 452-454, 458-459.

7. Centers for Disease Control, Division of Diabetes Translation. *Diabetes Surveillance, 1980-87.* Atlanta: US Department of Health and Human Services, April 1990.

8. Jerneld B, Peep A. Relationship of Duration and Onset of Diabetes to Prevalence of Diabetic Retinopathy. *American Journal of Ophthalmology* (1986). Vol. 102, No. 4: 431-437.

9. Klein BE, Moss SE, Klein R. Is Menarche Associated with Diabetic Retinopathy? *Diabetes Care* (October 1990). Vol. 13, No. 10: 1034-1038.

10. Agardh E, Torffvit O, Agardh C-D. The Prevalence of Retinopathy and Associated Medical Risk Factors in Type 1 (insulin-dependent) Diabetes Mellitus. *Journal of Internal Medicine* (1989). No. 226: 47-52.

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